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ABSTRACT

Case studies of three states were conducted to examine different approaches to the development of policies concerning early intervention, family support, and interagency provisions under Part H of the Individuals with Disabilities Education Act. The study utilized a qualitative methodology aimed at discovering grounded theory (theory generated inductively from collected data) and related policy principles. Findings, discussion, and recommendations are given for three areas addressed by the study: (1) state efforts to make the service system more formal as required by Part H; (2) state efforts to deal with the tension between uniformity and diversity within their systems; and (3) concordance between state goals and policies and between services and family needs. Findings suggest that family support policy is developing around the issue of legal entitlements associated with specialized populations, in this case infants and toddlers with disabilities or at risk for developing disabilities. Recommendations encourage open discussion of beliefs about families, legal entitlements, and other themes such as the relationship between the state level which has the legal responsibility for compliance and the community level where children and families are served. (Contains 22 references.) (DB)

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Carolina Institute for Child and Family Policy

TRUST, ENTITLEMENT, OR SOME OF BOTH: CAN THE PART H SYSTEM PROVIDE THE SUPPORTS FAMILIES NEED AND WANT?

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EC 301843

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Executive Summary

The family support and interagency provisions of P.L. 99-457, the 1986 Amendments to the EHA (Education of the Handicapped Act, now termed Individuals with Disabilities Education Act [IDEA]) are widely recognized as part of a broader paradigm shift related to the philosophy, structure, and context of services for individuals with disabilities and for their families (Senate Report, P.L. 102-119, p. 23). As indicated in previous Carolina Policy Studies Program (CPSP) documents, enormous challenges are faced by the state and local policy makers who have responsibilities for planning and implementing these family support components. There are a number of political, economic and professional barriers that may prevent the actual development of policies and eventual implementation of these policies in some states.

The attempts by states to develop these family-related provisions provide a rich context for examining the processes that are being undertaken to integrate family support constructs with traditional child-centered approaches in the development of effective and comprehensive early intervention services. A case study of three states that use very different approaches to the development of policies illuminates the wide diversity of processes and approaches to policy development.

Methodology

This study used an ethnographic research methodology to build and expand theory related to family supports that are provided within an early intervention system. The power of this approach to potentially greatly enhance understanding of the policy development process under Part H of the IDEA, the Early Intervention Program for Infants and Toddlers with Disabilities, is drawn primarily from comparing and contrasting divergent approaches in three states.

This study utilized a qualitative methodology aimed at discovering grounded theory (theory generated inductively from the data collected) related to family policy development under Part H. Grounded theory can provide a coherent set of principles to describe a phenomenon, but is valid only within the context that it is described. Therefore, the theoretical framework that was developed within this study is "grounded" within the context of policy development under Part H.

The three states chosen for the study came from a larger subset of six states chosen by the Carolina Policy Studies Program for a series of case studies designed to investigate the implementation of policies related to the provisions for finance, interagency coordination, and family policy in Part H of IDEA.

In this study, on family policy the authors formulated guiding, open-ended, questions on the basis of a review of the information in the literature. In a qualitative study, coding of data should begin with an open frame of reference so that codes can be created to match the data. In this study, codes from two coding schemes found in studies of family support or individual family service plan (IFSP) development provided the skeleton; we then added codes during analysis of the data obtained in interviews and state policy documents.

Since differences in policy development are as important as commonalties in policy development, a question with a certain theoretical orientation was posed and cases are examined to see whether that theory holds up in each instance. It is important to seek contrasts to truly test the robustness of the theory. The three states in this study were specifically selected for their potential to demonstrate contrasting case studies of policy development, and the results confirm their diversity.

Data for analysis was drawn primarily from three sources: (a) documents describing policies or program guidance relating to IFSPs, service coordination,[1] procedural safeguards, or other specific family support issues (e.g., state laws, applications for federal Part H funds, and Governors' reports); (b) interviews with key informants and participants in policy development in each state; and (c) incidental information about various aspects of policy development and implementation in each state, including direct observation of consumers and policy makers during site visits.

This report addresses three questions that arose from the data and from analyses of the literature: (a) How are states responding to the need to make the service system more formal, as required by Part H? (b) How are states attempting to deal with the tension between a uniform and equitable system and the affirmation of local diversity? (c) Are the goals that these states have for family provisions in their policies reflected in the nature of the policies, and how well do the services that are sanctioned by the states conform to what families say they want? For each question, the findings and discussion are briefly summarized below followed by recommendations.

Question #1: Formality versus Informality

How are states responding to the need to make the system more formal, as required by Part H?

Findings and Discussion

The results of our research suggested three themes of importance to policy development. The first theme dealt with the desire for, and the impact of, legalization of policies and practices. The second theme dealt with differences in approaches to the development of a formal legally accountable system and the way these differences might be related to the nature of trust relationships evident among key constituencies in the state. The third theme dealt with the importance that state constituents placed on the informal networks of support (e.g., parent-to-parent supports) available in the state and the role that the state intended these potential networks to play in Part H planning and implementation.

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[1] *During the site visit the term case management was used. The term service coordination is used in this report because of language changes during reauthorization.*

A picture of three very different state approaches and attitudes emerges. One state, Daylily,[2] minimally complies with Part H, overtly expresses the goal to de-legalize the system as much as possible, places a high priority on maintaining an emotional climate of trust (with the possible exception of certain governmental factions), and relies heavily on an informal network, which that state terms, "the underground," to plan and carry out Part H responsibilities. The second state, Rose, welcomes the legal and formal requirements of Part H with the law's explicit provisions to ensure equity and access to services; some distrust is apparent in Rose between state and local providers, but there is no visible sign of an underground. The third state, Queen Anne's Lace, falls between these two opposites.

Queen Anne's Lace proactively plans to create a fully integrated interagency system (i.e., it has a vision broader than the minimal requirements of the regulations). Key planners in Queen Anne's Lace report that they are resigned to having to make the system more formal and legal but describe a climate of trust. However, some examples of seeds of distrust were voiced in discussions of relatively recent crises as the system responded to the formal demands of change. Queen Anne's Lace seemed to ignore the underground. Queen Anne's Lace sees the underground as useful as a referral mechanism but not by playing a significant role in Part H planning.

Recommendations

The frustrating aspect of conducting policy analyses in real time, as the three states in the study are developing the polices, is that it is not possible to predict which of these scenarios will end up producing a system that can optimize the supports needed by children and families. Furthermore, these scenarios are built around the existing state culture, attitudes, political environments, resources, and individual state histories and agency traditions. Is there any reason to believe that building a system onto an underground of support will produce a system that suits the majority of families better than one that is derived from a formal, professionally driven, and systematic process of planning and implementation? It is possible that there exists some "goodness of fit" in each of these states between these contextual issues and the approaches to policy development. However, the sharp contrast in these approaches poses some questions and signals our attention to some significant implications for states as early intervention systems are developed.

Based on the intensity and interest that these topics engendered in the interviewees in this study, it seems particularly vital for key policy makers to target these areas; by providing vehicles for open discussion, perhaps those who influence policy can come to some consensus about goals for these areas. States should initiate forums to structure dialogue around at least the following aspects: Legalization of policies, Trust, and the Role of the Underground or the informal system of support and concern in the state. Some of the questions that still need answers are;

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[2] *Names of flowers were given to states, based upon unique attributes of each state, in order to provide anonymity.*

Legalization of policies.

1. What is our reaction to the fact that Part H requires a legally binding system of early intervention?

2. What changes does Part H require states to make to be in compliance, and what is the extent of a state's commitment to these provisions?

3. Is there a way to use procedural safeguards and other legal requirements to supplement a state's philosophy and approaches? How do states maximize the potential benefits and minimize the potential harm to the system that they desire?

Trust.

1. What is the nature of the relationships of key constituencies (state to local providers, parents to providers, states to parents, state to other state personnel, etc.)?

2. How has or does the nature of these relationships influence policy development? Are these relationships conducive to the type of Part H program that states desire?

Role of the underground:

1. What is the role of the *underground* in state policy development and program implementation? Is there a strong informal network and should it be a focus of Part H policy planning and implementation?

2. What type of emphasis should the state place on the informal network? Will this be sufficient to ensure appropriate and equitable services to families?

3. What is the role of the formal statewide parent-to-parent system of family support in relationship to the informal supports that individual families should have access to at the local level? Is it necessary to have a strong formal network to integrate the informal networks into the Part H policy planning process and to incorporate these networks into the early intervention delivery system?

Whether or not the policies and implementation will be qualitatively different between the states under study here is impossible to answer at present. The effects of these beliefs and decisions will be identified only when the programs have been in place for some time. However, given the dramatic differences in the three states under study here, self-examination of beliefs seems to be warranted in all states. In planning and implementing policies for families on a statewide level, it appears to be important to note the emotional climate and the existence of functional support networks. Strategies to achieve policies may be more effective if they are carefully woven around functional networks, not just the structural relationships, which are more obvious.

Question #2: Uniformity Versus Diversity

How are states attempting to deal with the tension between a uniform and equitable system and the affirmation of local diversity?

Findings and Discussion

The drive for uniformity in two of the three states is seen most clearly in the policies of the IFSP, but is also expressed to some extent in case management systems. One of these states plans to have a uniform IFSP, even though it has never had a statewide Individual Education Plan format for older children who receive special education services. Procedural safeguards, those elements of policy that ensure equity, are sometimes blamed for this drive to uniformity. Procedural safeguards were the least developed policy area and the last thing that people focused on in the interviews in each state. When procedural safeguards were mentioned, it appeared that respondents assumed that such questions referred to conflict resolution systems (reflecting the almost unanimous fear of state personnel of being sued by families). Additional questions were needed to probe for information that related to confidentiality, consent, and access to records. All three states are choosing to use Part B procedural safeguards (i.e., procedures established for school-aged children who need special education services).

When states attempt to allow local jurisdictions to develop policies that complement their localities, to act autonomously, and to ensure equitable access to services, they may need to become prescriptive at the individual family and system levels. Present study results suggest that these discussions should become overt and that the federal government and the states should examine in a forthright fashion how to develop policies that maximize the characteristics of systems (both state and local) but that still ensure that every child served under the system is treated justly, as due process under the constitution requires. The processes that are developed to monitor early intervention systems at the federal, state, and local levels are especially critical and there is a need to be creative to respond to unique family concerns and local characteristics as well as to ensure equity, access, and individualization.

States must look for flexibility wherever it can be found, as long as such flexibility also protects the rights of the families and children who are to benefit from this program. One of the ironies of this program is that it requires the system to be flexible at the local level to meet the diverse needs of families, but federal mandates also require compliance with very prescriptive requirements. Are these two incompatible goals?

Recommendations

1. Whenever possible, states should use outcome-based indicators rather than strict compliance with "the regulations." Are families getting what families say they want in the short term? What are the longer term benefits to infants and toddlers and their families who are served by the Part H system?

2. The federal government should endorse some mechanisms for state flexibility within this program. One of the inevitable consequences to the state concerning which policies are appropriate and which are not is a continually restricting set of rules that become more and more precise. As they become more precise, they become less and less able to fit the diverse circumstances within the state and within each family. Gallagher, the Director of the Carolina Policy Studies Program, has proposed that local communities be allowed to have 10% of their cases decided on the basis of individual professional judgment, without regard to specific rules, if local professionals feel that the rules do not match the circumstances. All of the professionals would have to sign off on such exceptions and would have to live with that decision. This is an example of a state having a flexible policy that would allow it to take into account the diverse circumstances that exist.

3. Funding mechanisms need to be analyzed to determine how to allow local providers to access funds that meet their unique circumstances, goals, and opportunities. Policies need to be analyzed to determine the constraints and requirements that the multiple federal programs place on states and local service delivery systems. Many federal programs are beginning to address the needs of infants and toddlers with special needs and their families, but the confusion and restrictions engendered by the regulations needlessly restrict how public and family resources can be used to best meet the needs of these families. The federal government must pay serious attention to contradictory and confusing eligibility requirements, allowable expenses, coordination of funding sources and other such matters.

Questions #3: Policies and Services

Are the goals that these states have for family provisions in their policies reflected in the nature of the policies? How well do the services that are sanctioned by the states conform to what families say they want?

Findings and Discussion

Goals and philosophies of states. To a significant extent, the written philosophies in each state overlap in areas, with common emphasis on: (a) whole family functioning, (b) the importance of the family's decision-making role, and (c) family-professional collaboration. These areas were also consistently verbalized by respondents in all states. However, there were some differences in terms of commitment to these principles, and these differences were correlated with some differences in policies (e.g., case management policies). The process of microanalysis of written philosophy statements in these three states, with active cross-referencing of interviewee statements and system plans, yielded surprising results. Although there appears to be surface agreement and many common beliefs among Part H policy makers, some differences in beliefs adhered to by constituents (including consumers) appear to have had a significant impact on the policy development and outcomes. Policy makers must be cognizant of the role of beliefs about families in the process of developing services for families with young children with disabilities. Discussions of these beliefs should become widespread to facilitate and nurture the most effective systems of support for families and young children.

Meeting the needs of families. Each of the three states addressed the need to consider the socioemotional aspects of intervening in the lives of members of a young child's family. The interviewees in the states talked about the need for a positive relationship with a significant early interventionist. States acknowledged the right of families to receive or be assisted in accessing emotional support for the family if it is desired by the family. However, the policies of the three states differed in the extent to which these issues were addressed.

Recommendations

1. States should make explicit what services are allowable to meet parents' needs, including any expressed need for social or emotional support or other such nontraditional early intervention services. In addition, given the intimacy of the early intervention relationship between parents and providers, states should acknowledge that a meaningful relationship between the family and the service provider should be encouraged. Such explicit recognition would serve as reassurance to the family and the providers.

2. States should ask themselves what mechanisms contribute to or hinder the development of a positive relationship between the family and the service provider? Perhaps the most important question is that offered by Janet Vohs, a member of the CPSP Family Advisory Committee, in a discussion of the subject of interpersonal relationships: "But do they let providers charge for it?" She explained that a particular type of activity might not have acceptability unless it was recognized as a billable time period.

   Policy makers are encouraged to consider ways to develop billing codes to ensure that interpersonal activities are sanctioned. Providers might well spend some moments in conversation or in otherwise establishing a meaningful rapport, but until this is acknowledged as a legitimate service, these will be moments most likely stolen from other approved, direct services, such as physical therapy. Physicians have recently adopted new coding procedures, that is, CPT codes, to respond to conditions when physicians need to spend time with patients, but not for technical procedures. Thus, there is a precedent for different kinds of billing codes.

3. The Part H system should design policies that formalize the appropriateness of assisting families to connect with their informal supports, including explicit information about the expenditure of Part H funds. Families may well receive support from informal sources, but under certain circumstances (e.g., the birth of a baby with special needs) they may need some assistance in accessing this informal support. Perhaps the family needs transportation assistance so it can travel across town to spend time with a trusted family member, or perhaps the family needs assistance in getting to a community facility so that the parents can take all of the children to some important community function in which they have always participated.

Background

Family support policy has been an increasingly visible mechanism that is used to establish structures and promote practices that specifically aim to strengthen the functioning of families of infants and toddlers who have or are at risk of developmental delays. The intent of family support policies is to promote optimal child outcomes. The principles of family support have evolved out of at least five separate movements (see Table 1). These movements may or may not be coordinated within a state. For example, the health system may be engaged in providing family-centered, community-based care for children with special health care needs, while another state agency may be developing specific family support systems that prevent the need for institutionalization of children and adults with disabilities. Although the philosophical frameworks of these two movements may overlap, the actions of the players at a state or community level may not, with the result being that many constituencies are unfamiliar with the range of family support concepts and programs being promoted by different service systems and advocacy perspectives.

Recognition of the importance of the principles of family support has emerged over time. These principles are beginning to be integrated into formal policies and have been explicated to an increasing degree in federal legislation. P.L. 99-457, the 1986 federal amendments to the Education for the Handicapped Act, included incentives for states to develop a comprehensive state system of early intervention services and contains some of the most explicit federal provisions related to the development of family-centered policies (Place, & Gallagher, 1992). Two of the major family support components of Part H of P.L. 99-457, recently reauthorized as the Individuals with Disability Education Act (IDEA; P.L. 102-119) are Individualized Family Services Plans (IFSPs) and service coordination (formerly termed case management).

The family support and interagency provisions of P.L. 99-457 are widely recognized as part of a broader paradigm shift related to the philosophy, structure, and context of services for individuals with disabilities and their families (Senate Report, P.L. 102-119, p. 23). At the same time, as indicated in previous Carolina Policy Studies Program (CPSP) documents (e.g., Place, Gallagher & Harbin, 1989; Place, Anderson, Gallagher, & Eckland, 1991; Harbin, Gallagher, Lillie, & Eckland 1990), state and local policy makers with responsibilities for planning and implementing these family support components face enormous challenges; some of the barriers may prevent the actual development of policies and the eventual implementation of these policies in some states. Despite the significant barriers that do exist, attempts by states to develop these family related provisions provide a rich context for examining the processes that are being undertaken to integrate family support constructs with traditional child-centered approaches in the development of effective and comprehensive services.

A recently published study by the CPSP showed that two critical policy areas for states that are beginning to develop family-centered policies for the Infant and Toddlers Program (Part H of IDEA) were identification of family strengths and needs requirements, and the IFSP. (Place,. & Gallagher, 1992). The importance of identifying family strengths and needs was reflected by changes in P.L. 102-119. The

TABLE 1

A Reference List of Family Support Movements

Development of community-based programs for supporting and strengthening family functioning (Weissbourd & Kagan, 1989; Zigler & Black, 1989

State government efforts to establish policies and programs to support all families of young children (Weiss, 1989)

Family-centered, community based philosophical orientation promoted by Federal Maternal and Child Health Bureau (Brewer, McPherson, Magrab, & Hutchins, 1989) to support families of health impaired and medically fragile children and adolescents

State family support initiatives for persons with developmental disabilities and their families (Knoll et al., 1990)

Family oriented practices in early intervention services for very young children with disabilities and their families (Bailey, Buysse, Edmondson & Smith,1992)

old language was replaced by language that calls for a family-directed identification of the family's priorities, concerns, and resources. The change was made largely as a response to vocal parents and advocates of families.

Jeanette Behr, a parent from Minnesota, was among the first to publicly complain about the provision related to the identification of the family's strengths and needs. In the fall of 1989, she testified at a hearing sponsored by the Division on Early Childhood of the Council for Exceptional Children, stating that this provision was a "cross between a pit bull and collie; first it bites you, then it goes and gets help." Ms. Behr's metaphor aptly describes the concerns of parents regarding the formalization of IFSP requirements. Most families want a collie in the Lassie tradition (i.e., one that is responsive, non-judgmental, and genuinely helpful) and see the potential misuse of some of the requirements of the IFSP as causing harm to the very families the law was designed to support.

Although it is anticipated that the new language will support a more family-friendly approach with increased family control of the process, parents' previously voiced concerns are still relevant. Indeed, in a study of family preferences for IFSPs, Summers et al. (1990, p. 20) found that: "The irony is that the informal, fluid process considered to be 'best practice' ... for the process of information gathering, may be incompatible with an effort to develop rules to assure those best practices are in place."

A number of recently published studies identified the goals that families have for their involvement with early intervention services (Heflinger, 1989; Able-Boone, Sandall, Stevens, & Frederick, 1992; Summers, et al., 1990). These studies were unrelated to each other, except that all used the focus group approach to elicit information about the goals that families identify regarding their interactions with the Part H system. One robust finding from each of the studies was that family members highly valued a positive relationship with the early intervention service provider. In an earlier study, a senior investigator for one of these focus groups identified a model for communication between parents and professionals (Able-Boone, Sandall, Lougtry, & Frederick, 1990). On the basis of this model, both parents and professionals would speak truthfully, comprehensibly, legitimately, and sincerely. Sincerity is characterized as dealing with the trust between the two parties, leading to a mutual understanding and trust between speaker and listener. "Understanding of the position of the other would lead to shared decision making" (Heflinger, 1989, p. 88), and the shared decision making would be associated with a positive relationship.

Many parents in each of the three groups also identified the need for emotional support, whether from the early intervention specialist, informal networks, or formal family support groups. A literature search conducted by Summers and colleagues (1990) raised their concern when they determined that many families indicated that what they wanted was somewhat different from what was being promoted by policy makers. Summers and colleagues noted that the preference for emotional support was not typically cited by state policy makers. This is consistent with another recent study, which found that the perceptions about the nature of family and early intervention services by state policy makers differ from those of consumers at the street level (Bailey, Buysse, Edmondson, & Smith, 1992). After considering why this

difference in perspective may have evolved, Summers and colleagues stating that "This study poses some critical challenges to the field," asked the following questions:

> How can we systematically develop and assure accountability of a national network of programs that closely replicates the informal, dynamic, and naturally-occurring process for collecting information that families prefer?
>
> How do we mandate and regulate emotional sensitivity and friendship? How can we conduct reliability checks on shared confidences and unspoken understanding?
>
> How can we break down the artificial distinctions between formal and informal support and develop practitioner roles characterized by professional competence and friendship? (Summers, et al., 1990, p. 21-22).

Another consistent finding from the three focus groups was that families wanted informality and flexibility in their relationships and in the nature of the support available to families. However, the families also relied on clarity and reassurance about what services they were entitled to receive, and wanted to know how to gain access to those services. Families in the study by Summers and colleagues (1990) explicitly placed a dual emphasis on both the nature of relationships with early intervention service providers and on the safeguards that ensure and monitor the services to which family members are entitled. Thus, it appears that from the family perspective, emphasis should be placed on aspects of goals to achieve informality as well as on other aspects for achieving clear and binding formal procedures.

The paradox of providing a formal system of family support that is characterized by informal modes of interaction has been noted by Dunst and colleagues in an earlier study of the utilization of early intervention services as a social support (Dunst, Trivette, & Deal, 1988). In a program evaluation of early intervention services, families described their relationships to their formal and informal social support networks and the nature of the support that they received. Surprisingly, the relationship to the early intervention service provider resembled the relationships that families had had with their informal network, but it did not resemble the relationship they had with providers of other, formal support services.

These findings make much sense when it is remembered that early intervention services have been described as an "intimate" service (Healy, Keesee, & Smith, 1989). However, there are gaps in the training traditions in the disabilities (Heflinger, 1989) and early intervention (Bailey, D., et al., 1989) fields that may produce mixed outcomes with regard to the abilities of early intervention service providers to establish effective therapeutic relationships. In addition, "intimacy" may be an incompatible concept for a bureaucracy that has as its essential elements hierarchy, specialization, rules, and impersonality (Dimonck as cited by Dyer, & Dyer, 1969).

The early intervention program in most states would not have been characterized as bureaucratic, rule-bound, or hierarchical. A variety of local units provided whatever services they had resources and authority to provide. However, if

the resources were exhausted or if what the family needed was outside their authority, families purchased the needed service themselves, were placed on a waiting list until the services became available or went without the services. This system worked, to whatever degree it did work, in part because there was mutual trust between the family and the providers and because the families were grateful to receive any assistance they could.

This approach was sanctioned by policy makers because they were faced with the diverse needs of families and service systems with differing capacities so the decision was usually to allow discretion and local autonomy so the local units could develop and carry out policies and programs. This had been the tradition for early intervention in many states prior to the passage of Part H (only seven states had mandates that guaranteed services to infants and toddlers prior to the passage of Part H). States have expressed a desire, and perhaps a real need, to continue to allow local jurisdictions the flexibility to develop early intervention programs that accommodate the unique characteristics and resources of the local community. Some state personnel indicated that if the policies handed down from the state to the local providers were too prescriptive, local units just would not be able to participate in the program or might even actively oppose the passage of the legislation or other authorizing policy in the state, which would seriously jeopardize the development of an early intervention system.

However, the passage of Part H requires states to ensure that every child and family has equal access to all services to which they are entitled and that requires each family be provided with a basic core of services. At a minimum, states must ensure that all families receive a comprehensive evaluation of their children, that families are provided procedural safeguards, and that states must conduct child find activities. In addition, these services must be provided by professionals who meet the highest personnel standards in the state. Many states that originally had the desire to include at-risk children in the Part H program retreated from this concept when they became aware that they would have to provide some uniform level of service to all eligible children and that the state could be sued if it did not provide this basic level of uniform service. For every eligible child and family, the state must ensure that it meets the mandated requirements for the identification of the family's concerns, priorities, and resources as they relate to the development of the eligible infant or toddler, development of an IFSP (which meets detailed federal requirements), and delivery of all services listed in the IFSP for which the agency is responsible.

The detailed requirements of Part H demand a formal system of policies that describes a certain level of uniformity of interaction with the family. This move toward a more bureaucratic structure conflicts with the desire to accommodate local autonomy and diversity. If local units determine the nature of their systems on the basis of their own circumstances, might some jurisdictions determine that all eligible children receive only home-based services and never have access to center-based programs? Might not programs develop a standard that all eligible children who need physical therapy receive the service only once a week, regardless of individual need? The variations are limitless.

The legislation and regulations for the Part H system are quite prescriptive and would not allow such diversity as indicated in these examples. The Infant and Toddler Program was authorized as an entitlement program (i.e., every eligible child and family must be provided the services they need as listed on the IFSP). Procedural safeguards were included to guarantee that equity of access to early intervention services is ensured for every eligible child, regardless of where the child lives, by whom the child is served, the type or severity of the child's disability, the type or amount of early intervention needed, or the status of the agency's fiscal or personnel resources. If a family believes that the child and/or family is not receiving some service to which they are entitled, the family has the right to use the formal complaint resolution processes that the state must have in place.

Thus, there is a real and dynamic tension between the authorizing of local units to develop programs that optimally match the needs and goal of their unique community and the ensuring that all eligible children throughout the state receive equitable services. This need to ensure equitable treatment of all eligible children might require a state to systematize services that were historically quite diverse and that may well have an established history of local autonomy. Indeed, Harbin, Gallagher, & Batista (1992), noted that as states began to deal with policies and processes to accommodate the requirements of the law, they began to adopt increasingly bureaucratic ways.

This report will respond to three critical policy questions that emerge from the literature and the data.

Question 1. Formal versus informal systems: The three states in this current study relied, in some part, on an informal system of early intervention services prior to passage of Part H. How are these three states responding to the need to make the system more formal, as required by Part H?

Question 2. Uniformity versus diversity: How are these three states attempting to deal with the tension between a uniform, equitable system and the affirmation of local diversity?

Question 3. Policies and services: Do the goals that these states have for family provisions in their policies reflect on the nature of the policies? How well do the services that are sanctioned by the states conform to what families say they want?

Michelle Marlow, a parent in Baltimore, Maryland, provided the following testimony at a U. S. Senate hearing in March 1991, regarding the IFSP:

> The family is the natural caregiver, and as we move forward with the implementation of part H, we must move with great care to guarantee that it does not become yet another specialized system of services which has the potential of being crippled, by "administrative convenience." If the IFSP is individualized on paper only, we have lost. You have before you a program that is of critical importance to the lives of thousands of infants born each year with disabilities. Please make sure it works for them

(Senate Report to accompany S. 1106, later adopted as P.L. 102-119, p. 5).

Her testimony underscores the importance of the broad question that frames the present study: Is the development of a formal support system for children with disabilities and their families antithetical to the nature of the informal, flexible, and emotionally responsive supports that are needed? Is Part H a policy paradox with no chance of accomplishing its diametrically opposed goals?

Methodology

The present study is part of a larger four-year study of policies that have a direct impact on families. Previous activities have included multiple year telephone surveys to determine the nature and status of states' policies in relevant areas and a report contrasting two very different states as those states dealt with policy development in this area. The current study is based on site visits conducted in the spring of 1991. The analysis became influenced by a striking consistency of findings from focus groups of families in various parts of the United States.

Ethnographic Research

The present study used an ethnographic research methodology to build and expand theory related to family supports provided within an early intervention system. This approach is consistent with the grounded theory methodology proposed by Glaser and Strauss (1967). A grounded theory has been defined as "one that is inductively derived from the study of the phenomenon it represents" (Strauss, & Corbin, 1990, p. 23): that is, it comes from the ground up. Although a theoretical framework guided the formulation of initial research questions and data collection, responses to open-ended questions were analyzed throughout the study in order to formulate theory. New questions were generated throughout the data analysis process by using this grounded theory approach. As new questions were posed, data were reexamined to verify the emergent theory. An inductive mode of reasoning was primarily utilized; that is, possible explanations or theoretical formulations were eliminated when they were found to be inconsistent with the data.

Three-state variables. The power of this approach to potentially greatly enhance understanding of the policy development process under Part H is results primarily from comparing and contrasting divergent approaches in the three states being studied. We deliberately chose these three states because they represented very different characteristics. The contextual variables studied included the degree of system change desired, structure, history, politcal climate, wealth, human service problems, and homogeneity of population.

To protect anonymity, we substituted the names of flowers for the states. Daylily refers to a first state in the study, because Daylilies capture the essence of independence combined with a strong underground propagation system. Rose, the name assigned to the second state in the study, characterizes the formality and complexity one might find in a cultivated garden. Queen Anne's Lace describes the third state that relies on a lovely but fragile interconnectedness of complex, independent structures and repeating patterns.

Although the three states do not fully represent the policy making process of all states under Part H, the comparison of these three will illuminate themes along a continuum of development of specific family policies that overlap with the continuum of policy development of many other states. A secondary approach that supports the reliability of the findings is the triangulation of data, in which different sources of information are used to verify the conclusions. In addition, the use of two investigators to analyze the data provides for the objectivity of an outsider and the needed subjectivity of the primary investigator who had direct contact with the key respondents.

Data for analysis were primarily drawn from three sources: (a) documents describing the policies or program guidance relating to IFSPs, service coordination,[3] procedural safeguards, or other specific family support issues (e.g., state laws, applications for federal Part H funds, and Governors' reports), (b) interviews with key informants and participants in policy development in each state, and (c) incidental information about various aspects of policy development and implementation in each state, including direct observation of consumers and policy makers during site visits.

Interviewees. In each state, the Part H coordinator was provided with a list indicating the type of respondents targeted for the study and likely participants for interviews. The investigator was impressed in each of these three states by the diversity and breadth of the population made available for confidential interviews during the site visits. Such representation substantiates the findings derived from the interviews, because these were individuals with a major influence on policy development in that state. The cooperation from the Part H coordinators in these states is evidence of their interests in providing accurate and comprehensive information about the nascent Part H program in each of their states.

The site visit to Daylily was made in March, 1990. Interviews of 11 state personnel, parents and advocates, and providers occurred during the three days. Each interview lasted for at least an hour. In addition to individual interviews, the senior author was invited to observe a state Interagency Coordinating Council (ICC) meeting and participate in a pilot monitoring activity. The site visit to Rose was made in late November, 1990. Interviews of nine state policy makers occurred. In addition, the investigator attended a statewide conference targeted to family members and other interested parties, during which state policy makers arranged sessions at which the CPSP staff could interview groups of parents about their experiences with the new Part H system of identifying family strengths and needs and developing and implementing IFSPs. For the site visit to Queen Anne's Lace, nine people were interviewed in December, 1990. The investigator was also able to observe an ICC meeting during the site visit.

The primary author conducted interviews and recorded key statements during the site visits. The initial framework for questions that guided interviews in these three

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[3] *During the site visit the term case management was used. The term service coordination is used in this report because of language changes during re-authorization.*

TABLE 2

INTERVIEW DATA CODING FOR THIS STUDY

EARLY INTERVENTION PROGRAM PRINCIPLES

- Emotional sensitivity to families
- Acknowledging the family as the ultimate decision-maker
- Acknowledging diversity and meeting individual family preferences
- Promoting interagency coordination and service coordination
- Enhancing social support
- Communicating clearly and completely
- Advocacy for family rights and services
- Considering whole family strengths, needs, and involvement
- Building a foundation for the future

IDENTIFICATION OF FAMILY STRENGTHS/NEEDS

- Informality
- Content of family strengths/needs identification
- Who should identify family strengths/needs
- Immediate and complete feedback
- Ongoing, continuous process
- Use of creative strategies
- Home visits

EXPECTED OUTCOMES OF EARLY INTERVENTION FOR FAMILIES

- Meeting family information needs
- Meeting needs for whole-family and individual well-being
- Enhancing parent-child relationships
- Enhancing family-professional relationships

(Summers, et al., 1990)

states centered on the goals for family policy among key members of the state decision-making constituency (including parents and advocates). The senior author posed the following questions:

1. What are the goals for the development of policies related to IFSPs, service coordination, procedural safeguards, etc.?

2. How do you see these goals being accomplished?

3. How likely is it these goals will be accomplished?

Interview data coding. The second author coded and initially analyzed written records of the interviews. A review of a number of previous studies on IFSP implementation and family policy led to a decision to use categories from two existing studies. Codes were drawn from the results obtained with focus groups by Summers et al. (1990) (see Table 2) and from family support principles as delineated by Dunst et al. (1991) (see Table 3).

As we analyzed the interviews, we added additional codes. Some of these were pulled from other existing categorical schemes (Harbin et al., 1990). We also added codes if pertinent issues for which another existing code did not adequately portray the intended meaning that was brought up during the interviews. In addition, the findings of Summers et al. (1990) provided another dimension for analyzing the data. A possible tension between the formal and informal process provided an overall framework that guided the coding of the data. A specific question was initially posed regarding this continuum: "Is the development of a formal system antithetical to the provision of social support?" Some items might have been coded under a specific family support principle and might therefore have been coded as informal or formal, depending upon the context in which the principle was incorporated. For example, regulations about identifying family strengths and needs might have been coded formal simply as a result of the specific content area from which these regulations emerged, whereas in another context, they might more appropriately have been coded informal.

A number of Summer's coding did not appear at all in the interviews: thus, the final coding scheme does not directly resemble that Summers et al. (1990) even though it was the starting point for the data analysis. In addition, certain organizational schemes were posed and then dropped when they were found to be insufficient or if the hypotheses did not hold up to theory testing. For example, an initial formulation was proposed that services on the IFSP and service coordination should fall under the rubric of "social support." The process for achieving these services (e.g., timelines) and the process for safeguarding these processes or procedures all fell under a separate rubric. This scheme did not fully capture the formal versus informal continuum, nor did it address the beliefs that might powerfully under gird the policy making process.

The final codes generally fell into four overarching categories: family support principles and outcomes, structure, process, and components. The final coding scheme is depicted in Table 4. The codes that arose from the interview data in each state were recorded separately and then aggregated into one coding scheme. The

TABLE 3

CODING SCHEME FOR FORMAL VERSUS INFORMAL INTERVIEWS

Six Major Categories and Examples of Family Support Principles

1. **Enhancing a Sense of Community**
2. **Mobilizing Resources and Supports**
3. **Shared Responsibility and Collaboration**
4. **Protecting Family Integrity**
5. **Strengthening Family Functioning**
6. **Proactive Human Service Practices**

(Dunst, C., et al., 1991, p. 117)

TABLE 4
OVERALL CODING SCHEME

FAMILY SUPPORT CONSTRUCTS

Principles and Beliefs Embedded in Goals for Family Policy

- Protecting Family Integrity
  - Allowing differences, cultural diversity/flexibility, meeting individual family needs, whole family orientation, (Preventing breakdown of family)
- Family rights/entitlement (Legal remedy)
  - Zero reject
- Shared responsibility and collaboration
- Belief/source of change
- Prevention of parent burn-out
- Emotional sensitivity./need for support
- Building a Foundation for the future
- Consumer orientation (proactive principle (Dunst)
  - (Strengthening family functioning)
- Trusting relationships
- Family/ultimate decision maker
- Enhancing sense of community
  - Fantasy - informed service system providers, interconnected, accessible and informative

Principles Embedded in Goals for Early Intervention Program Components:

- Mobilizing Resources and Support
  - (Enhancing social support)
- Meeting family information needs
- Informal identification of family strengths and needs

STRUCTURE

- Interagency coordination
  - dispute resolution
  - forms
  - eligibility
  - culture
- Existing services (history)
- ICC authority/role
  - to set culture
  - Change - burnout./turnover
  - Membership

- Funds
  - accountability
  - abuse
  - tied to program
- Flexibility
- Governor

- State/local relationship
  - local variation
  - street level
    - vacuum
    - chaos and confusion
- Family friendly
- Standards
  - Intent violated
- Decision making
- Seamless
- Geography

PROCESS (STRATEGIES/BARRIERS)

- Underground
- Timing
- Leadership (contextual relationships)
- Bureaucratic
- Ambiguity
- Constituency building
- Parent liaison
- Access/Need for information
- Advocacy
- Informal vs. formal
  - legal remedy
  - parent-to-parent support
  - meetings
  - rules
  - Overbearing system
  - Culture - distrust for rules, distrust for too much
  - flexibility without oversight
  - inconsistency
- Controversy
  - clash on family philosophy
- Formal/planned strategies (vehicles)
  - creativity/innovation
- Consensus process to develop IFSP document
- Communication
- Person to person

COMPONENTS

- IFSP form
  - ongoing process
  - "Brief" IFSP -id of family strengths and needs, etc., (scope/timing)
  - flexibility/no form/ensure consistency
  - tied to funding/Medicaid
  - inconsistency with family focus philosophy
- Procedural safeguards
  - timelines
  - parent's right to refuse services
  - confidentiality
  - mediation
  - referral
- Case management (decision) (controversy)
  - structure
  - nature/functions
  - financing
  - dependability and consistency (e.g., child find, access)
  - Identification and referral
  - Fuzzy thinking -personality/numbers
  - personnel standard
  - conflict of interest/direct service provider
  - relationship to team members
  - Triage - complexity of child need
  - Ongoing/evolving role
- Evaluation team
- Transition
- Service - respite care, transportation, etc.
- Monitoring policy
  - Quality vs. compliance

number of categories within each of the four larger groups is extensive. Decisions were made to focus on specific questions that arose from the data because of their relationship to the questions guiding the study. These decisions were not made lightly. Data were revisited and reconstructed along different lines (i.e., case groupings [state-specific data] and thematic groupings) to build the most durable theoretical framework. This approach uses what is referred to in qualitative research as "axial coding," a second tier of coding after the initial open coding occurs (Strauss & Corbin, 1990). Both are part of the analytical process.

Helpful to the analytical process was the fact that some new codes originating in individual states were different enough to quickly generate comparisons as a rich source of information. When one state did not have a frequently stated or poignantly cited issue or code, the immediate question was Why not? For example, in this study, two questions presented themselves toward the end of the open coding process: trust was mentioned in two states but not in the third. Also, the same two states described or cited evidence of an underground (informal) system.

Document analysis. Once we derived the categories from interview data, we analyzed the written policies that were available at the time of the site visits, to verify emergent theory. The categories that were the focus of the written policy analysis were: philosophy statements about families, services that were indicated as appropriate entitlements under the Part H program, and services that addressed the dilemma between standardized policies and local autonomy. These categories were chosen as foci because of the initial questions posed by the study and because the interview coding process generated questions related to themes of beliefs, principles, equity, uniformity, and diversity. We analyzed primary documents--that is, laws, regulations, and official reports (e.g., reports to the governor from the ICC). In addition, if guidance on any of the three targeted topics was unavailable from primary documents, we examined program guidelines for references to the targeted topics. The formality of the policy that is used therefore becomes an important issue. We have highlighted the type of policy referred to in this report so that the reader will know the status of the policy that is used as data.

Results. We used interview data and analyses of policies to address the policy questions identified in the introduction to this report. For each question, we first present the findings from the analyses and then immediately follow these findings by discussion and recommendations.

Question #1: Formal versus Informal Systems

Three states, Daylily, Rose, and Queen Anne's Lace, relied, in some part, on an informal system of early intervention services prior to passage of Part H.

Question 1: How are constituents responding to the need to make the system more formal, as required by Part H?

Findings

Prior to the passage of Part H, all three states had provided some early intervention services to some families and children. In two of the states, very few, if

any, children had an entitlement to services. For the most part, children and families received the services that were available. One state had an entitlement program prior to Part H but was planning to extend the entitlement to a much larger portion of the population than before. The children who would be newly entitled to services under Part H had been receiving services from a variety of providers on a more ad hoc basis, depending on the child's diagnosis and the available resources. These service delivery systems usually did not have a strong legal foundation and were much more informal in terms of enforceable policies.

However, the passage of federal legislation and the promulgation of federal regulations required participating states to formalize what had previously been informal. Part H requires states to guarantee that all rights and protections be afforded to all eligible families and children. Services must be appropriate, individualized, and equitable. All staff must meet the highest standard for the profession or discipline that provides intervention services. The state must assume the responsibility of developing standards to meet the federal requirements and to monitor and ensure that all personnel are in compliance with the standards.

We analyzed data from interviews to determine what the interviewees identified as the ramifications resulting from the state's response to the need to move toward a more formal and legally binding system of services. Analysis revealed that three themes were embedded in their conversations. The first theme related specifically to entitlement, and/or the need for a legal remedy. A second theme, the issue of trust, emerged as a critical feature as the system became more formal. A third theme dealt with the significance of informal networks of supports for parents.

Part H as a legal remedy. Respondents in both Rose and Queen Anne's Lace believe that a legal remedy must be provided for families to guarantee the provision of early intervention services. In Rose, respondents went so far as to state that "procedural safeguards are the cornerstone of effective implementation in this state." In sharp contrast, in Daylily, a legal remedy was valued by only one respondent (a parent): "I feel comfortable knowing that if I ever had to, I could take this to the letter of the law." All other interviewees in Daylily stated that this legality was detrimental to the type of service delivery system the state was committed to and that the state's goal was to de-legalize the system: that is, "we can set the tone so it won't look like legal jargon." Almost to a person, those in Queen Anne's Lace were in between the two polar positions of states Rose and Daylily. Interviewees in Queen Anne's Lace wanted some legalization of the system but with a user-friendly program.

In the interviews, we found the word "entitlement," which for many is descriptive of a legal guarantee for services with the concomitant right to sue if such services are believed to be denied, to be somewhat emotionally charged. For example, in Queen Anne's Lace, even when there was a clear statement of the importance of a legal remedy for families, there also was the observation that "the use of the word entitlement . . . changes the tone" of the service delivery system. The interviewees in that state consistently voiced concerns that having an entitlement would move the system away from one in which parents and professionals work together to provide whatever they can to meet the needs of children and families to a system in which the parents were adversaries of the service system. In the remaining states Daylily and

Rose, the imposition of an entitlement program was also viewed as a mixed blessing. There was acknowledgment that an entitlement could provide some additional safety for families; for example, state legislators were less likely to be able to cut the budgets of a federal entitlement program; but there was also a keen awareness that this entitlement could lead to divisive and protracted legal complications.

Trusting relationships. A theme that arose out of the interview data in two states was the issue of trust. Interviewees in both Daylily and Queen Anne's Lace made numerous strong statements about trust even though the interviewer made no prompts to lead the interviewees in this direction. Reaction of the three states to Trust follows.

In Daylily, trust for parents was well articulated: "What is strong about this place is that we really trust parents. We lay our hearts open and trust. The way to modulate the system is to have trusting relationships that empower parents." Providers in Daylily showed that they had a high level of trust for the primary decision-makers at the state level. At the time of the case study visit in Daylily, however, the state's policies were in a much less advanced stage and providers had not yet had to modify the ways that they provided services.

In contrast, trust was never specifically cited in the state, Rose. Given the importance of this concept in two of the states, the absence of the use of the term, "trust" stimulated the question, "Why is trust not mentioned?" Possible explanations include the following: (a) Some interviewees' implied a distrust of providers, and some even implied a distrust of parents, and (b) responses favored the establishment of formal processes for carrying out the IFSP and other Part H provisions. This suggests that "trust" might occur in a more formal context in Rose or that the lack of trust might strengthen the goal for a more formal and legally binding system.

In Queen Anne's Lace, one interviewee stated that "we can trust families; we can trust each other . . . [in this state, we] take care of each other." Another interviewee commented: "Parents are very responsible and aware of agencies' fiscal constraints. Let parents prioritize" the services that they need.

In Queen Anne's Lace, trust of public agencies was also mentioned. Distrust of specific state structures was explicitly stated. A state level respondent said they "have a great working relationship with the community so that we haven't had people reneging on services." However, some people in Queen Anne's Lace were concerned about some providers. One interviewee pointed out that "people are assigned responsibilities and are supposed to communicate and update [state agency personnel] at least quarterly. But sometimes this doesn't happen. We find out by accident that a family's been dropped." Some respondents described a misguided use of funds that led them to recommend that safeguards be in place to keep local personnel from making decisions that were in reality a conflict of interest.

Providers in Queen Anne's Lace discussed concerns that they might not be able to trust state personnel, and there was strong resistance to what the local providers saw were state-imposed restrictions and demands. This created a climate of tension at the time of the site visit to Queen Anne's Lace. The feeling on the part of state personnel in both states Queen Anne's Lace and Daylily was that the providers

were having or would have a hard time adjusting to the Part H changes initially, but hope was expressed that things would turn out alright "in the long run."

The significance of informal networks. Formal and informal networks of parent support were discussed in every state, sometimes as structures by which to carry out services under Part H and sometimes as vehicles of communication that influence policy development. This issue emerged as one of the goals in Daylily, because a number of respondents believed in the underground (informal network) of parent-to-parent support. The belief that it is important to have a law to guarantee or entitle services for young children with disabilities and their families appears to be at odds with the belief stated in Daylily that the most important goal is to protect the informal support system that exists for families. Respondents in Daylily cautioned that when systems "come on that formal, families hide from the system." Some respondents expressed a desire to continue to meet families' needs by building on the acknowledged informal system. In Daylily, one state policy maker expressed the popular opinion that "a vast underground of parent-to-parent support, both formal and informal," exists, and that "we must not sabotage these" relationships. Somehow, policies in Daylily would be built on this underground network but nobody was able to describe how this was to be accomplished.

Even in Daylily, however, where the concept of an underground appears to be universally acknowledged, there is not universal agreement about its value. One member of the ICC asked, "Why do we have to rely on the underground? Why build a network on a fragile system?" It is interesting to note that Daylily was the only state to have very active formal parent-to-parent organizations that were very involved in the policy development for Part H.

An interesting contrast was provided by Rose. One of the explicit goals for policies in this area was the establishment of a formal system of parent-to-parent support. The lack of any active family-to-family support network was cited as an issue, because this state desired a strong constituency representing parents in the policy development process. This state, therefore, devoted resources to the creation and support of a very formal network so that state policy makers could have feedback from families as they developed their Part H policies. What impacts, if any, that the Part H service delivery system might have on existing informal networks of support did not emerge from the interviews.

Some evidence for the existence of an informal network was found in Queen Anne's Lace; even though it was not recognized as such by the respondent: "We are getting lots of referrals from parents but we don't know who tells them." In that state, although an underground network of professionals and parents appeared to exist, its utility was not seen as a means of implementing Part H. Increased referrals were desired, but the explicit plans for accomplishing this was through the development or expansion of a more formal mechanism of case management. Perhaps some interviewees implied the suggestion of informal support networks when they related how communities tend to take care of their own. This informal network was not very overt, however. Thus, the presence of the underground was only a semiconscious recognition, and it is not surprising that there was no commitment to preserving this "underground" as there was in Daylily. It must be noted that there was no active,

organized, formal network representing parents who act in an influential role in policy development.

Discussion

Part H as a legal remedy. An important dialectic appears to occur between the opposing dimensions of formality and informality in both the process of developing family policy and the structures that exist or that are created to carry out policy. This movement back and forth is seen in the choice of beliefs and principles that guides the development of goals for family policy and that specifies the strategies for achieving those goals (e.g., activities for the development of formal legally binding structures or for the empowerment of informal advocacy systems..

Some tension around the task of legalizing the system was evident in all of three states, but to different degrees. Daylily and Queen Anne's Lace were resigned to the need to formalize the early intervention system, but they varied in their levels of commitment to legalizing the system. Daylily intends to do the minimum necessary to meet the federal requirements: "Whether we like it or not, the application [for federal Part H funds] requires us to write down processes, so we will have to define these processes." Queen Anne's Lace is making more changes and is dealing with the effects of the federal requirements. In the third state (Rose), however, the rules are welcomed. There does not appear to be active tension about rules and procedures. Rather, there appears to be overall acceptance of the need for some formalized structures; the "issue is to make sure rights are protected."

Trusting relationships. Differences in approaches to the development of a formal legally accountable system might be related to the nature of trust relationships evident among key constituencies in the state. Regarding the legalization of the system, Daylily and Queen Anne's Lace directly discussed trust; in Rose, comments merely alluded to its absence. The issue of trust was not part of the questions in any interview. In Daylily, the state with a strong commitment to the least formal and legal system, conversations frequently included comments about state personnel trusting families and local providers trusting the state. However, Daylily was the least advanced in policy development vis-a-vis Part H requirements; thus, fewer changes in delivery of services had occurred, which is in contrast to the other two states. Both state personnel and consumers in Rose made explicit comments that the policies had to be very formal so that the rights of consumers could be protected. Queen Anne's Lace was midway between a desire for or against the level of formality for the system and was also somewhat ambivalent in terms of trusting relationships.

It may be that when service systems appear to be working well, less concern is placed on legal remedies. A number of intriguing questions arise when looking at this trend. When systems of rights and formal conflict resolution (i.e., procedural safeguards, especially the right to an impartial hearing) fully evolve in Daylily, will there be a change in the apparent climate of trusting relationships? Will formal and legalistic systems be more likely to ensure that families receive appropriate services than was the case at the time of the interviews? Does the existence of a safety net (i.e., the right to an impartial hearing) allow families and personnel to reach new levels

of trust? Is trust a state resource that should be valued and nurtured? A study of a larger sample of different states would shed valuable light on this emergent issue.

Significance of informal networks. Some proponents of social support theory postulate that access to support is enhanced by strong informal personal networks and is to be preferred over a system of professionalized supports. Informal networks, -- or, as some states called them, "underground networks," serve both as vehicles for communication for parents and as access pathways. This theoretical construct pervades the comments made by interviewees in Daylily. Priority was placed both on using the underground network to implement services and to capture the essence of the underground to serve as a foundation for input into policy development. However, Daylily was also the state with the most powerful and well-organized formal parent to parent support network. In Rose, by contrast, it was noted that the development of a formal system of parent-to-parent support was a high priority since no informal system existed either to be used to provide direct support to parents or to serve as a vehicle for policy development. In Queen Anne's Lace there was unconscious testament to an informal system but no direct plans to incorporate this into Part H policy planning or implementation was identified. No formal parent-to-parent organization was identified, nor did the need for this emerge from the interviews. Whereas, some constituencies in some of the states were focused on how to minimize the disruption of informal networks, others were expressing concern that reliance on these networks might be a risky proposition.

Recommendations

As the three states in the study are developing the policy, the frustrating aspect of conducting policy analyses in real time, is that it is not possible to predict which of these three scenarios will end up producing a system that optimizes the supports needed by children and families. Furthermore, these scenarios are built around existing state culture, attitudes, political environments, resources, and individual state histories and agency traditions. Is there any reason to believe that building a system onto an underground network of support will produce a system that suits the majority of families better than one that is derived from a formal, professionally driven, and systematic process of planning and implementation? It is possible that there exists some "goodness of fit" in each of these states between these contextual issues and the approaches to policy development. However, the sharp contrast in these approaches poses some implications and questions. The data described in the current report, supplemented by the data acquired in previous studies and in interactions with many states, serve as a basis for some implications and recommendations for states developing early intervention systems.

On the basis of the intensity and popularity that discussions about formalizing the early intervention system engendered in the interviewees in the present study, it seems particularly vital for key policy makers to target these areas for discussion. States should initiate forums to structure dialogue in the areas of: part H as a legal remedy, trusting relationships, and significance of informal networks. Note appropriate questions associated with each area.

Part H as a legal remedy.

1. What is our reaction to the fact that Part H requires a legally binding system of early intervention?

2. What changes does Part H require us to make to be in compliance, and what is the extent of our commitment to these provisions?

3. Is there a way to use procedural safeguards and other legal requirements to supplement our philosophy and our approaches? How do we maximize the potential benefits and minimize the potential harm to the system we desire?

Trusting relationships.

1. What is the nature of the relationships of key constituencies (state to local providers, parents to providers, states to parents, state to other state personnel, etc.)?

2. How has or does the nature of these relationships influence policy development? Are these relationships conducive to the type of Part H program we desire?

Significance of informal networks.

1. What is the role of the underground in our state policy development and program implementation? Is there a strong informal network and should it be a focus of Part H policy planning and implementation?

2. What type of emphasis should the state place on the informal network? Will this be sufficient to ensure appropriate and equitable services to families?

3. What is the role of the formal statewide parent-to-parent system of family support in relationship to the informal supports that individual families should have access to at the local level? Is it necessary to have a strong formal network to integrate the informal networks into the Part H policy planning process and to incorporate these networks into the early intervention delivery system?

Whether the policies and implementation will appear to be qualitatively different between the states under study here is impossible to answer at present. The effects of these decisions will be identified only when the programs have been in place for some time. However, given the dramatic differences in the states under study here, self-examination of beliefs seems to be warranted in all states. In planning and implementing policies for families on a statewide level, it appears to be important to note the emotional climate and the existence of functional support networks. Strategies to achieve policies may be more effective if they are carefully woven around functional networks, not just the more obvious structural relationships.

Question #2: Uniformity versus Diversity

Question 2: How are states attempting to deal with the tension between a uniform and equitable system and affirmation of local diversity?

Findings

There is a real and dynamic tension between authorizing local units to develop programs that optimally match their unique community needs and goals and ensuring that all provisions of Part H legislation and regulations are available for all eligible children and families. The need to ensure equitable treatment of all eligible children might require a state to systematize services that historically were quite diverse and that may well have enjoyed an established history of local autonomy. The findings below address this tension between diversity and uniformity of service provision.

Daylily. At the time of the site visit to Daylily there were no written policies about the procedures that programs must follow. The state was funding pilot projects in communities across the state and planned to replicate projects that proved to be effective. Information about these effective elements would be disseminated to a variety of targets, including families. In the report from the ICC to the Governor, one of the goals of the early intervention system was to "use existing resources in creative and flexible ways that allow for differences in individual communities." In that same report, the ICC pledged to "ensure that services and supports for infants and toddlers and their families reflect the philosophy of the ICC: that families have the ability to identify their own needs and have access to public and private resources to meet those needs." How these assurances were to be carried out was not described in that report.

Creativity as a strategy or even an outcome is consistent with interview data from Daylily. One of the interviewees commented that the guidance given to the staff at local sites was designed to "try to encourage providers to think creatively about the IFSP process." Another answered, "We permit innovation." For example, if generic providers are going to serve children with special needs, "we'll provide technical assistance on site in place of tuition for children with special needs. That way, we don't need to write rules for tuition."

Again, a review of the written policies about the IFSP offer a valuable look at the direction Daylily appears to be moving towards. The report issued by the ICC to the governor stated that the IFSP development process was to be flexible, family-focused and non-intrusive. Also, the process was to be dynamic and ongoing. Written policies of several pilot projects were provided during the site visit. These policies depicted quite diverse approaches to the development and the content of the IFSP. The written policies of these projects also indicated that the services they would provide to the families varied among pilot projects.

Rose. The written policies of Rose best exemplify the conflict between the need for flexibility to allow programs to be individualized for families and the need for standards to ensure equitable access to services. The law in this state requires that a local ICC be established in each local jurisdiction to "administer the interagency

system of early intervention services in their subdivision, under the direction" of the lead agency.

An overview of the Annual State Application for Rose's federal Part H funds indicates that the state has developed policies and procedures to facilitate and enable community-based planning. In a report of activities to date that was submitted to the Governor in 1990, the agency reported that there was "general agreement the system should . . . be able to support different local service delivery models." The report says that the best way to meet the state's goals is to give "maximum flexibility to local jurisdictions." "At the same time," continues the report, "the state has an interest in ensuring the provision of certain core services on a statewide basis and ensuring accountability for outcomes. Existing systems, both within and outside the state, do not provide a model for local flexibility that assures accountability." This conflict between a goal of local autonomy and the reality of the current system at the local level was exemplified by the blunt statement that there was "no interagency coordination at the local level."

The annual report included a proposal that Rose address this conflict between local flexibility and ensuring equity. It recommended that a number of sites be funded to pilot a new proposal development and approval process. The report provided significant detail on this process. In summary, it would require that all proposals to the state be submitted by a multi-constituency group responding to state established goals and parameters for the use of funds. The state would also establish outcomes to measure the success of each proposal and would monitor the success of the models. After the pilot sites provide the state with data, the state would then determine how to allow local jurisdictions flexibility while ensuring the provision of equitable services to all children.

Because the state policy makers (including influential parents) could not assume equitable treatment, the state opted for uniformity in the IFSP and the development of a statewide IFSP form. A state policy maker commented on the fact that "Blank paper could be so subjective. The counties also wanted a form. If we didn't have a form, some counties would give a lot of services and some none."

At an established date, all children in the state were to be "provided with early intervention services through the [state's] IFSP Document and Process." The original draft IFSP form contained a lot of white space and seemed to leave a lot of leeway for the team. After piloting and discussing this draft IFSP, the form was re-written. The Performance Report for Year 2 explains that a draft form and process had been developed with the assistance of pilot projects. "A direction that was selected during the year was for a single form to be implemented statewide, rather than for each [jurisdiction] to develop a different form."

The current form is much more formal and institutional looking than that which was first proposed and is much more prescriptive for the IFSP team. It is 16 pages long, has 8 pages of very detailed instructions and 8 pages that are to be filled in with required data. The form is accompanied by a 13 page description of the requirements for the IFSP process, including requirements for who should be involved at each step in the process, who is responsible for the action, how each step is to be carried out,

what decision options are available, what procedural safeguards apply, and what data are to be collected during that step. Interviewees reported that one of the factions that was most influential in systematizing and elaborating on the IFSP was the very vocal parent constituency in the state. Families were concerned that if the form was vague, some communities would carry out the Part H program as intended by the federal and state government and some would not.

Queen Anne's Lace. The state law in Queen Anne's Lace gives the state agency responsibility for the governance of the system of early intervention services and specifies that this authority shall not override the authority assigned to the local jurisdictions. However, that section of the law that describes the authority of the local providers indicates that the lead agency should develop regulations that specify the responsibilities of the local providers. The proposed regulations in Queen Anne's Lace that would govern the provision of services under the Part H program state that the early intervention system is "committed to the greatest level of flexibility, creativity, and personalization of the service delivery system". The regulations also reiterate the requirements of the federal law that mandate that every child deserves equal access to services.

The proposed program guidelines assert that the goal of the guidelines is to ensure the consistency (emphasis added) and high quality of all programs. However, despite the goal for consistency, the guidelines also state that they are intended to allow for program diversity. These program guidelines consist of 28 single-spaced pages of guidance that must be met by some if not all providers. The guidelines appear to be quite specific about how programs should be operated and if implemented would ensure consistency among programs that formerly acted as diverse entities with little regulation imposed on them by the state. Thus, there appears to be some conflict among the written policies in Queen Anne's Lace. This conflict was mirrored in statements by those interviewed. "Everyone is in agreement that the IFSP will be identical to ensure similarity of services." However, many others wanted to be able to develop their own IFSP forms and other paperwork and were upset that the state was imposing such an intensive format on all of the providers. Such sentiment was explicated in the following comment: "We don't want to be regimented but we need to know where we have flexibility and where we don't."

A review of the written policies focusing on the development of the IFSP provides a vehicle by which to examine the degree of consistency desired by the state. In Queen Anne's Lace, there is a separate set of guidelines for the development of the IFSP that are quite detailed and comprehensive. The description about the contents and process of developing an IFSP is 23 pages long. This includes 9 single-spaced pages of instructions and a 12-page draft IFSP, with the remainder of the document dealing with other relevant information. The document itself is not explicit about whether or not every program in the state is to use the same form, but the interviewees indicated that this is being considered. The draft form was being piloted at the time of the site visit. The directions include 10 major components broken down into an additional 29 required elements. Most of these elements describe the federal law's requirements but expand on these to reflect the state's philosophy of service provision.

The length and potential impact of this IFSP form concerned some respondents in Queen Anne's Lace. One key informant stated that "the [guidelines] are now supposed to have the weight of law. But they weren't originally intended to do so."

This strategy represents a quite significant shift in what had previously been sanctioned by Queen Anne's Lace. Local sites were given great latitude in their development of program plans prior to the changes provoked by the Part H program. As indicated above, interviewees expressed serious concern about the imposition of such comprehensive and prescriptive policies affecting their operations. The guidelines and the regulations were making formal what had been operating as a much more informal and very autonomous service delivery system. The comprehensiveness of these policies in Queen Anne's Lace seems to be a reflection of the conflict between allowing systems to individualize their programs and the need to ensure consistent service delivery to every eligible child and family throughout the state.

Discussion

The drive for uniformity is seen most clearly in the policies of the IFSP, but is also expressed to some extent in case management systems. States were furthest along with IFSP policy development, relative to other components, at the time of the interviews. In at least one state, there was a verbalization of the need to create a uniform case management system. In another state, there was a goal for uniform services, the state had not decided how to do that but was discussing the possibilities. Procedural safeguards were the least developed policy area and the last thing that people focused on in the interviews. When procedural safeguards were mentioned, it appeared that respondents assumed that questions referred to conflict resolution systems. Additional questions were needed to probe the questions that related to confidentiality, consent and access to records. All three states choose to use Part B procedural safeguards.

Daylily, consistent with its general approach for local diversity and individualization, allows communities to develop their own IFSP processes and formats.

The written policies in Rose exemplify the dilemma inherent in Part H policy development. Originally, analysts of Part H asserted that one of the goals of the law was to optimize the state's authority in developing the Part H system, for example, the governor was to designate the lead agency which he or she decided was most appropriate to administer this program. However, when the federal administration attempted to ensure that all infants and toddlers and their families in every state received equitable treatment, the application for federal funds for this program was extensive and, as reported by many states, was extremely prescriptive about major and minor policies.

The development of Rose's IFSP document serves as a classic depiction of the conflicts that arise when an attempt is made to meet both the need for local autonomy and the need to ensure equity throughout the state. The state had originally planned to provide each local jurisdiction with a fairly open-ended format for the IFSP. However, the document that was reviewed during the site visit was long and very

detailed. Explicit instructions for completing the plan were included with the form and were very prescriptive. Information about procedural safeguards is one of the first pieces of information that the family encounters. There appears to be a very restricted possibility for local variations in the form or the process.

As reported above, these changes primarily came about because of vocal recommendations from the parents, who stated that unless the form specified all the information that served as a basis for this program, some families would receive the services to which they had a right and others would not. A very detailed and user-unfriendly form evolved because of a statewide distrust of the local service systems.

In Queen Anne's Lace, local sites were given great latitude in the development of plans prior to the changes provoked by the Part H program. The strategy depicted by interviewees in Queen Anne's Lace represents a quite significant shift from what had been sanctioned by the state. Interviewees expressed serious concern about the imposition of such comprehensive and prescriptive policies affecting their operations. The guidelines and the regulations made formal what had been operating as a much more informal and very autonomous service delivery system. The comprehensiveness of these policies in Queen Anne's Lace seems to be a reflection of the conflict between allowing systems to individualize their programs and the need to ensure consistent service delivery to every eligible child and family throughout the state.

Recommendations

When states allow local jurisdictions to develop policies that complement their localities, that is, to act autonomously, the need to ensure equitable access to services may cause the policies to become prescriptive at the individual family and system levels. The present report cannot prescribe a remedy to this dilemma. We suggest that discussions become overt and that the federal government and the states examine in a forthright fashion how to develop policies that maximize the characteristics of systems (both state and local) but that still ensure that every child served under the system is treated justly, as due process under the Constitution requires. The processes developed to monitor early intervention systems at the federal, state, and local levels are especially critical, and there is a need to be creative to respond to family concerns for emotional support as well as equity, access, and individualization.

States must look for flexibility wherever it can be found, as long as such flexibility also protects the rights of the families and children who are to benefit from this program. One of the ironies is that although this program requires the system to be flexible at the local level to meet the diverse needs of families, the federal mandates also require compliance with very prescriptive requirements. Are these two incompatible goals?

Some specific recommendations follow:

1. Whenever possible, states should use outcome-based indicators rather than strict compliance with "the regulations." Are families getting what families say they want? What are the longer-term benefits to infants and toddlers and their families who are served by the Part H system?

2. The federal government should endorse some mechanisms for state flexibility within this program. One of the inevitable consequences to the state concerning which policies are appropriate and which are not is a continually restricting set of rules that become more and more precise. As the rules become more precise, they become less and less able to fit the diverse set of circumstances within the state and within each family. Local communities should be allowed to have 10% of their cases decided on the basis of individual professional judgment, without regard to specific rules, if local professionals feel that the rules do not match the circumstances. All of the professionals would have to "sign off" on such exceptions and would have to live with that decision. This would allow for a flexible policy to take into account the diverse circumstances that exist.

3. Funding mechanisms need to be analyzed to allow local providers to access funds that meet their unique circumstances, goals, and opportunities. The federal government should give serious attention to contradictory and confusing eligibility requirements, allowable expenses, coordination of funding sources, and other such matters.

Question #3: Policies and Services

Question 3: Do the goals that these states have for family provisions in their policies reflect on the nature of the policies? How well do the services that are sanctioned by the states conform to what families say they want?

Findings

Written goals and philosophies of state policies. What do the philosophies contained in written policies about the identification of family strengths and needs, the IFSP and service coordination in each state and reports from interviewees indicate about the perspective that states have regarding families? The data from each state are presented below. Table 5 displays codes related to statements of belief or philosophy made by respondents during the interviews.

During the interviews (see Table 5), at least one interviewee provided responses that indicated that one aspect of the belief system in the state was that families must be the ultimate decision maker. The interviews also suggested the importance of shared responsibilities; in complicated situations, parents weren't to be left to search for their own resources but should be partners with the case manager and other professionals. This was somewhat of a compromise position resulting from the acknowledgement that there were not sufficient resources to assist every family: "We'll handle the more difficult situations, after that the families are on their own." The compromise seemed to be acceptable because there was a notion that most families could handle their own case management. No one mentioned that the family was considered a major source of change in this state. This finding is consistent with the observed situation in the state during the site visit. Families were highly valued, but their consistent and influential involvement in policy development was negligible.

Written policy statements that provide the framework for the statewide system specify that an overall guiding principle that influences all policies is the involvement

and empowerment of families. In a report from the ICC to the Governor, the ICC stated that empowering families, connecting families with supports and enabling them to reach for their dreams were the goals that the ICC had set for the Part H program. The values (identified in that report) that would guide the development of Part H policies included such items as a focus on the needs of the child within the context of the family, a recognition that parents are active and equal partners in making decisions, and the need to provide choices and options of services.

These beliefs were echoed in the interviews. One statement indicative of Daylily's position was the following: "What families need is empowerment, the power to be able to make comments and decisions." Interviewees also suggested that families are a major source of change in the policy development process. Policy development was seen as being driven by parents' expectations: "Our strategy is that by creating a knowledgeable parent constituency, we will have more referrals and involvement and then we will have documented an expanded need. We can't expand the system if we can't show the need." The interviewees also acknowledged that families provided the last word in decision making in the context of child and family services (see Table 5).

The law in Rose states that: "The policy shall be to promote a stable, safe, and healthy environment for children and families, thereby increasing self-sufficiency and family preservation. This requires a comprehensive, coordinated interagency approach to provide a continuum of care that is family and child oriented and emphasizes prevention, early intervention, and community-based services." The state published a mission statement in its overview of the proposed application for Year 4 federal funds. One point in the short statement addressed families: "to facilitate family and professional collaboration in the planning and implementation of comprehensive policies and programs that will provide support to infants and toddlers and their families." Specific principles are detailed in the application.

During the interviews in Rose, there appeared to be a strong desire for the development of a formal system of services. Parents were credited with playing a significant role in the development of state policies and as being important partners in all programmatic decision making (see Table 5). No one mentioned that the family was the ultimate decision-maker, however.

The law in Queen Anne's Lace reports as one of its commitments the responsibility to empower parents through the early intervention process so that they can fully participate or choose not to participate in the early intervention program. The state has a written statement of philosophy for its program that focuses solely on the role of the family. A summary of this statement follows: Family focused early intervention means that families and professionals collaborate (a) to recognize and respect the family as the central focus in their children's lives and in the early intervention process, and (b) to enhance families' capacities to meet the special needs of their children who have disabilities or who are at risk of acquiring disabilities, by recognizing families' strengths, and enhancing families' capacities to identify their own needs and to make or change their own decisions.

Table 5

Beliefs and Principles Embedded in Goals for Family Policy in Three States

	Rose	Daylily	Queen Anne Lace	Source of Codes
Protecting family integrity allowing differences, cultural diversity/flexibility	X	X	X	Dunst/Summers
Building a foundation for the future	X	X	X	Summers
Enhancing a sense of community (Interagency collaboration)	X	X	X	Dunst
Shared responsibility and collaboration (Parent/professional relationship, Case management)	X	X	X	Dunst
Belief that parents are the source of change	X	X		Summers
The family is the ultimate decision-maker		X	X	Summers
Importance of legal guarantees for family rights	X		X	Derived
Proactive human service practice (i.e., consumer orientation/strengthened family functioning)	X	X	X	Dunst
Importance of trusting relationships		X	X	Derived
Parents need for emotional sensitivity and support	X	X		Summers
Importance of preventing parent burnout	X	X		Derived

Meeting the needs of families. As specified in the introduction to this report, many families have consistently asked for certain interactions from the system that are qualitatively different from traditional early intervention services. These have included the often-expressed need for supportive relationships with some person in the early intervention system and the need for emotional support from either the early intervention system or elsewhere. Do state policies address or allow the early intervention system to meet these needs of families? An analysis of state guidance for the development of the IFSP provides an illustration of states' written policies with regard to allowable services vis-a-vis what families have identified as some of their highest priorities, that is, the need for a positive interpersonal relationship and emotional support. Do the policies that describe sanctioned roles and services reflect the importance of relationships and emotional support?

Since specific services and functions of early intervention staff in Daylily were not detailed in Daylily's written policies, there is no way to determine whether or not the state would sanction the use of Part H resources to meet these needs of families. The goals, values, and policy statements contained in the report from the ICC seem to indicate that such a focus would be appropriate. Certainly, some of the written policies of the pilots encouraged these types of activities. For example, functions of the home visitor were described in an informational packet for families in one pilot project. In addition to the more traditional functions of a home visitor, the parents were informed that they could expect the following functions of the staff: "listen to your questions and your feelings about being a parent; . . . help you to be a more confident parent; . . . talk to you about the changes a baby has brought to relationships with others." These typify the kinds of positive interactions and support that many of the families in the focus groups described and that previously seemed to have been missing.

One concept that was identified in Daylily during the interviews was the need to support families, with a fairly consistent emphasis on acknowledging and utilizing informal sources of support. However, state policies were not going to prescribe how the programs at the local level would provide or assist families in accessing this support. As an example, no state models of case management were offered. Rather, components were to be recommended. The interviewees indicated that the services would "absolutely" vary at the local level. The goal was that families would be involved in the development of local policies and programs to ensure an appropriate role for families. Training of case managers was to be emphasized to deal with this lack of state regulation.

Support was also a strong theme in Rose. The mission statement included in this state report declares: "The mission ... is to ensure that family and professional collaboration is the foundation upon which all planning and implementation of comprehensive policies and programs are built. All programs should be designed to support infants and toddlers and their families through accessible, coordinated, family-centered, community-based, individualized, and flexible service and support systems."

Another state report that describes the state's efforts to support families, describes one of its principles as follows: "The identification of a family's strengths and needs must be based on an individual family's determination of those aspects of their family life most relevant to their child's development." When discussing the role of the

case manager and the IFSP process, a document developed by the state says "To say that effective communication is the key to successful case management is to understate the situation. The need for a positive ongoing interactive process cannot be overemphasized." The first stage in case management identified in this document is "engaging." "The purpose of engaging is to establish rapport with a family and to create a base on which to build a future relationship. Depending on the results of evaluations, this relationship may be intense ..."

Rose's IFSP does not include a list of services that should be considered for the IFSP, but there are instructions to identify the outcomes that families would like to see for the child or themselves and to describe the strategies that will effect these desired changes. While these excerpts do not deal with whether or not personal supports are allowable functions, the policies cited above certainly imply that such activities would be sanctioned.

Three of the potential services listed in the draft IFSP in Queen Anne's Lace overtly or presumably deal with parents' needs for personal support. Included in the list are: "parent education and support" (emphasis added), "mental health" and "social services." In addition, non-binding policies for the development of the IFSP in AA state that "the IFSP should identify strategies to help families mobilize or use informal supports to meet identified needs."

Discussion

Written goals and philosophies of state policies. To a significant extent, the written philosophies in each state overlap in areas with common emphasis on: (a) whole family functioning, (b) the importance of the family's decision-making role, and (c) family-professional collaboration. These areas were also consistently verbalized by respondents in all states. However, the repeatedly expressed belief of "family empowerment" in Daylily stands out when compared to statements by respondents in Rose and Queen Anne's Lace. In Daylily, the written philosophy implements this belief system by clearly stating the value of "providing choices and options." In Queen Anne's Lace, the philosophical statement: "to enhance the family's capacity to identify their own needs and to make or change decisions," may result in more empowered families, but the statement appears to be based on the assumption that the impetus for this increased decision-making role could come from outside the family.

The very different systems envisaged for case management in Daylily and Queen Anne's Lace are perhaps the product of the rather subtle difference in execution of a philosophy of family support. In Daylily, there is consensus that case management will vary locally, perhaps almost to the individual level. In Queen Anne's Lace, case management is thought of as an augmentative service, to be provided according to the complexity and the level of need. The presumption is that a professional is involved in making that determination of need. Rose, in contrast, envisages a more standardized system of case management, which is embedded within the written statement of policy: "comprehensive, coordinated, and continuum of care." Rose, like Daylily but unlike Queen Anne's Lace, had respondents who stated the belief that families are the source of change. It is of interest that this belief is consistent with both formal and informal approaches to policy development and implementation or can occur independently of either of these orientations.

Microanalysis. The process of microanalysis of written philosophy statements in the three states, with active cross referencing of interviewee statements and system plans has yielded surprising results. Although there appears to be some agreement and many common beliefs among Part H policy makers (a core of consensus), some differences in beliefs adhered to by policy makers (including consumers) appear to have had a major impact on policy development. It is important that policy makers be cognizant of the role of beliefs about families in the process of developing services for families with young children with disabilities. It is recommended that discussions of these beliefs become overt to facilitate and nurture the most effective systems of support for families and young children.

Families who are asking for and professionals who are advocating an emotionally rewarding relationship with families should be somewhat heartened by the findings of the analysis of documents in each of the three very different states examined in the present study. Each of the states addressed this need to some extent. Although it is not official policy, one of the pilot projects to which the study investigator was directed in Daylily was the most explicit about the type of interpersonal interactions that families could expect from the Part H home visitor. Even in legally minded Rose, emotional needs are specifically dealt with in policy statements. Case managers are to be informed that successful case management depends on effective communication and that this communication may require an intense relationship with the family. The list in Queen Anne's Lace calls for the provision of parent education and support and mobilization of informal supports to meet families' needs. Queen Anne's Lace implicitly communicated the need for responsive relationships with families, but it did so without specific guidance. By failing to make this goal explicit, it might not be effectively communicated to providers.

Recommendations

1. States should make explicit what services are allowable to meet parents' needs, including any expressed need for social or emotional support or other such nontraditional early intervention services.

Given the earlier discussion about the intimacy of the early intervention relationship between parents and providers, states should not have to rely on the confirmation from focus studies that a meaningful relationship between the service provider and family should be encouraged. There was some latitude or encouragement for the development of a positive relationship and the capacity to meet families' emotional needs, if such assistance is requested by families. Microanalysis was required in most cases, however, to substantiate those findings. States should make explicit the fact that they place a high value on relationship building and maintenance. In addition, states must make explicit the role of Part H in meeting the nontraditional needs that families may not identify and for which they seek support.

2. States should make explicit the types of support a family can expect from the Part H system. This would serve as reassurance to the family and the providers.

3. States should ask themselves what mechanisms exist that contribute to or hinder the development of a positive relationship between the family and the service provider.

Perhaps the most important question is that offered by Janet Vohs, a member of the CPSP Family Advisory Committee, in a discussion of the subject of interpersonal relationships: "But do they let providers charge for it?" She explained that spending time establishing a relationship or providing support would not be considered credible until time spent in those activities became recognized as an allowable and billable time period. Providers might well spend some moments in conversation or in otherwise establishing a meaningful rapport, but until this was acknowledged as a legitimate service, these would be moments most likely stolen from other, approved, direct services, such as physical therapy. Policy makers are encouraged to consider ways to develop billing codes to ensure that interpersonal activities are sanctioned. Physicians have recently adopted new coding procedures to respond to conditions when physicians need to spend time with patients, but not for technical procedures. This provides a precedent for different kinds of billing codes.

4. Families may well receive support from informal sources but under certain circumstances (e.g., the birth of a baby with special needs) they may need some assistance in accessing this informal support. Perhaps the family needs transportation assistance so that they can travel across town to spend time with a trusted family member, or perhaps the family needs assistance in altering a community facility accessible so the parents can take all of the children to some important community function in which they have always participated. The Part H system should design policies that formalize the appropriateness of assisting families in connection with their informal supports, including explicit information about the expenditure of Part H funds.

CONCLUSIONS

This study in three states of the development of policies to support families within the early intervention program expands our theoretical understanding of the processes that are being undertaken to develop services for young children and their families with respect to Individual Family Services Plans (IFSPs), case management or service coordination, and procedural safeguards under Part H of the IDEA. The central dynamic in and among these states related to tensions, and/or differences in the creation of formal vs. informal policies and procedures. This was particularly notable in relationship to: (a) differences in beliefs about the impact of legal entitlements, (b) the existence of trusting relationships in policy development and service provision, and (c) the value given to informal networks of support (i.e., the *underground*) or formal parent to parent supports. A variation of the formal/informal dynamic was seen in the conflict between efforts to create uniform structures (e.g., lengthy IFSP statewide forms) versus the need to allow for local diversity and autonomy. Goals for policies and services also fell along a continuum with differences seen in beliefs about families and how they can best obtain and receive help. Although the states did pay some attention to families' need for emotional support and a trusted, intimate provider, procedures for obtaining support were sometimes paradoxically absent.

Based upon this grounded theory approach, it appears that the development of family support policy within an early intervention framework may depart from other movements to develop family support policy around the issue of legal entitlements. Legal entitlements are typically associated with a specialized population. In this case, the need to formalize procedures is directly related to the legal entitlement that is part of the legislation creating Part H. The population under Part H, infants and toddlers with disabilities or at risk of developing disabilities is a population that may have highly specialized needs and that have formed a distinct underserved part of the population. Whereas family support principles from parallel and previous family support movements are embedded within discussions of family support policies, certain beliefs about family support and traditions in therapeutic approaches are potentially at odds with highly formalized bureaucratic procedures to meet legal, regulatory requirements. And yet, the legal right to services appears to be viewed as an important cornerstone of the family support policies being developed.

The findings of this study suggest that family support policy development under Part H cannot be approached superficially. Recommendations revolve around the issue of bringing into open discussion aspects related to beliefs about families, legal entitlements, and other themes found in the study (i.e., a climate of trust, informal supports, and uniformity vs. diversity). These issues have particular significance to questions about the relationship that exists between the state level where the Part H legal mandate must be assured, and the community level where families and children are served.

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